

## Abstract

### **The Evaluation of a Self-Management Physiotherapy Programme for Adults with Cystic Fibrosis.**

**Introduction:** Cystic Fibrosis (CF) is the most commonly inherited life limiting disease in the Caucasian population. It is the result of mutations affecting the gene which encodes for a chloride channel known as the cystic fibrosis transmembrane conductance regulator (CFTR) and is essential for the regulation of salt and water movements across cell membranes. Defects in this mechanism cause increased viscosity of secretions, chiefly in the lungs and the intestinal tract. This abnormality results in the early onset of progressive chest infections, intestinal mal-absorption and malnutrition. Physiotherapy is an essential part of the treatment and management of CF as it aims to minimise progressive lung damage by ensuring that the airways are as clear as possible and that a healthy lifestyle is maintained through exercise/activity. Adherence to physiotherapy is a well recognised problem. This study aims to investigate what these problems are from a patient's perspective and to design a Self-Management Physiotherapy Programme (SMPP) to help improve the ability to adhere to physiotherapy treatment.

**Methodology:** The study initially used an action research approach as it actively involves the participants in the research process so that the problems of adhering to physiotherapy could be understood from their perspective. The methodological tools selected were a semi-structured interview and a survey in the form of a self-completed questionnaire that was issued before (Pre-Intervention Physiotherapy Questionnaire) the implementation of the SMPP and after (Post-Intervention Physiotherapy Questionnaire) to monitor any changes in adherence behaviours which may have occurred as a result of its use. The study group **comprised** the total full care patients ( $n = 61$ ) in an Adult CF Specialist Centre of whom 55 were eligible to be in the study and of these 49 agreed to participate.

The study involved two sets of semi-structured interviews, involving a total of eight purposively selected participants, representing a range of adherence behaviours, so that they could describe in their own words what problems they were having in adhering to physiotherapy and what having CF meant to them. The interviews were analysed and the findings informed the development of the questionnaires and the SMPP. The findings identified the significance of health beliefs and the perception of having CF on adherence

behaviour. These factors were taken into account when developing the questionnaire and the design of the SMPP. Following the analysis of the semi-structured interviews it was decided that the involvement of the participants to the level that is required in action research was not necessary. The study process continued broadly following the action research cycle of plan, intervention, evaluation and reflection. The Pre-Intervention Physiotherapy Questionnaire was developed and after piloting it was issued to the study population (n = 49) of whom 43/49 (87.7%) completed it. The SMPP was implemented and reviewed at three months and finally at six months after its implementation. Each participant was empowered to work in partnership with the researcher/physiotherapist in order to encourage self-management and potentially improve adherence. Barriers to adherence were identified and addressed through patients education. The SMPP's effectiveness in improving the ability to adhere to physiotherapy treatment was monitored using a Feedback Chart and the Post-Intervention Physiotherapy Questionnaire to capture their opinions.

**Results:** The study was completed by 29/49 (59.1%) participants. The analysis of the questionnaires and the participant's positive comments regarding the effectiveness of the SMPP indicated that there was a moderately increased trend in adherence following its the implementation. Although the results were not of statically significant they were of clinical importance. It appeared that health beliefs and the perceptions of having CF influences adherence behaviour. Education, empowerment and working in partnership with the researcher/physiotherapist to design their own individually tailored SMPP optimised the ability to adhere to physiotherapy treatment

**Conclusion:** The SMPP can be postulated as a new model of physiotherapy clinical practice that optimises the ability to adhere to physiotherapy treatment.

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## Abbreviations

ACPRC	-	Association of Chartered Physiotherapists in Respiratory Care
ACPCF.	-	Association of Chartered Physiotherapists in Cystic Fibrosis
ACBT	-	Active Cycle of Breathing Technique
ACT	-	Airway Clearance Techniques
AD	-	Autogenic Drainage
BMI	-	Body Mass Index
BMJ	-	British Medical Journal
C.F.	-	Cystic Fibrosis
COPD	-	Chronic Obstructive Pulmonary Disease
CPD	-	Continuing Professional Development
CSP	-	Chartered Society of Physiotherapy
DoH	-	Department of Health
EBP	-	Evidence Based Practice
FEV <sub>1</sub>	-	Forced Expiratory Volume in one second
HBM	-	Health Belief Model
I.P.P.B.	-	Intermittent Positive Pressure Breathing
MCIST	-	Medical Compliance the Incomplete Stories Test
N.H.S.	-	National Health Service
PEP	-	Positive Expiratory Pressure
QoL	-	Quality of Life
RCT	-	Randomised Control Trials
R <sub>s</sub>	-	Spearman's rank Correlation
U.K.	-	United Kingdom
U.S.A.	-	United States of America
WHO	-	World Health Organisation

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## Publication and Dissemination

The opportunity arose for some of the preliminary work for this study to be presented at local, regional, national and international conferences.

### *Presentations*

1. **World Conference Cystic Fibrosis – Jerusalem 1996.**  
Evaluation of Physiotherapy Services.  
C. Ireland, C.J. Rolles – Oral Presentation.
2. **European Respiratory Society – Geneva 1998.**  
Audit Strategies to Improve Physiotherapy Services for Cystic Fibrosis.  
C. Ireland, G.I. Connett, C.J. Rolles – Poster Presentation.
3. **World Lung Conference – Florence 2000.**  
Bronchomalacia in School Aged Children Managed by PEP Physiotherapy.  
C. Ireland, J.O. Warner – Oral Presentation and Poster
4. **European Cystic Fibrosis Conference – Genoa 2002.**  
Adherence to Physiotherapy in Cystic Fibrosis – A Literature Review  
C. Ireland, M. Carroll – Oral Presentation and Poster.
5. **Association of Chartered Physiotherapists in Cystic Fibrosis Annual Conference – Cardiff 2002.**  
Educational Strategies to Improve Adherence to Physiotherapy in Cystic Fibrosis - Invited speaker.
6. **Wessex CF Group Regional Study Day - Southampton 2002.**  
Adherence to Physiotherapy and Quality of Life - Invited speaker
7. **European Cystic Fibrosis Conference – Belfast 2003.**  
Adherence to Physiotherapy and Quality of Life in Cystic Fibrosis.  
C. Ireland, M. Carroll - Poster Presentation.
8. **World and European Cystic Fibrosis Conference 2004 – Birmingham 2004.**  
The self-management physiotherapy programme: Shall we take out a contract?  
C. Ireland, M. Carroll –Poster Presentation
9. **Maidstone and Tunbridge NHS Trust - Physiotherapy Department 2006**  
Adherence to Physiotherapy in Cystic Fibrosis - Lecture
10. **Oxford Radcliffe NHS Hospitals Trust - Physiotherapy Department 2008**  
The evaluation of a self-management programme: a literature review – Lecture
11. **Oxford Radcliffe NHS Hospitals Trust – Members of the Trust Executive Board 2010**  
The Role of the Physiotherapist in the NHS – Lecture

### ***Publications***

- Ireland, C. (2003). Adherence to physiotherapy and quality of life for adults and adolescents with cystic fibrosis: a literature review. *Physiotherapy*, 89(7): 397-407.
- Stevenson, et al., (2007). Intermediate care - Hospital-at-Home in chronic obstructive pulmonary disease: British Thoracic Society Guideline. *Thorax* 62, 200-210. (Contributing author).

## **DECLARATION**

**I declare that, whilst registered as a student on the Professional Doctorate in Health Sciences (DHealthSci) at the University of Portsmouth, I have not been registered for any other award at another university. The work undertaken for this degree and the results and conclusions embodied in this thesis are my own work and have not been submitted for any other award.**

**Christina Collins-Gilchrist**

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